DOCUMENT RESUME

ED 330 166 EC 300 138

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TITLE A Guide for Developing Self-Help/Advocacy Groups for Parents of Children with Serious Emotional Problems. Workbook Series for Developing Self-Help/Advocacy Groups for Parents of Children with Serious Emotional Problems.
INSTITUTION Georgetown Univ. Child Development Center, Washington, DC. CASSP Technical Assistance Center.
SPONS AGENCY National Inst. of Mental Health (DHHS), Rockville, Md.
PUB DATE Apr 87
CONTRACT MCJ-113806-01-0
NOTE 43p.
AVAILABLE FROM CASSP Technical Assistance Center, Georgetown University Child Development Center, 3800 Reservoir Rd., N.W., Washington, DC 20007 ($4.00).
PUB TYPE Guides - Non-Classroom Use (055)

EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS *Child Advocacy; *Emotional Disturbances; *Parent Associations; Parent Counseling; Parent Participation; *Program Administration; *Program Development; Self Help Programs

ABSTRACT

This workbook is a guide for the development of self-help/advocacy groups for parents of children and adolescents who have serious emotional problems. The workbook offers background information and then offers guidelines for: (1) creating a beginning plan for the development of a self-help/advocacy group; (2) developing concrete plans for accessing parents of children with emotional problems; (3) dealing with barriers faced in organizational development; (4) identifying agencies and professionals in the community that serve children with emotional problems and determining their level of commitment to parents; (5) writing an agenda for the first parent meeting; (6) developing ideas for the group's direction after the first several meetings; and (7) developing an idea of what the group will do together. Appendices contain examples of promotional posters and flyers, examples of newspaper notices, and a list of eight references and national organizational resources. (JDD)

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A GUIDE FOR DEVELOPING SELF-HELP/ADVOCACY GROUPS FOR PARENTS OF CHILDREN WITH SERIOUS EMOTIONAL PROBLEMS

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Prepared by

Georgetown University Child Development Center
Washington, DC
Grant # MCJ-113806-01-0

April 1987

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ACKNOWLEDGMENTS

The authors would like to especially thank the parents of children with emotional problems in the states of Kansas and Pennsylvania who were so willing to share their experiences and be involved in the initial efforts to identify the needs of their children.

Special thanks go to Cindy Boatman of Kansas for her continued consultation and her dedication to her stepson and other parents in Kansas; the people in the Children and Adolescent Service System Program (CASSP) family who have supported the involvement of parents in the process of providing the best possible services for these special needs families, especially Judy Katz-Leavy in the National Institute of Mental Health and John VanDenBerg formerly of Kansas; Mr. Donner's colleagues at the University of Kansas, School of Social Welfare for their consultation; Ms. Fine's colleague Robert Lerner of the Mental Health Association of Southeastern Pennsylvania for his continued support of the Parents Involved Network Project; and to Phyllis Magrab, Ph.D. of the Georgetown University Child Development Center for having faith in us and giving us the opportunity to share our work with others.

INTRODUCTION

This workbook is a guide for the development of self-help/advocacy groups for parents of children and adolescents who have serious emotional problems. It is not meant to be a recipe book, but rather a guide to help parents and mental health professionals who are interested in developing these much needed groups. Suggestions for the development of self-help/advocacy groups comes out of the authors' experience and learnings in Kansas and Pennsylvania.

The authors assume that the readers and organizers of these groups have a commitment to the idea that parents and professionals must be supportive of one another in their endeavors to organize parent groups. The time has come for parents of children and adolescents with serious emotional problems to end their isolation and to join together with other parents for mutsupport, to become effective advocates for their children and to work as allies with professionals on behalf of all children with serious emotional problems.

This workbook deals with both support and advocacy. A rather succinct definition of these two terms follows:

> SELF-HELP is defined as a group of people with a common problem who meet in a mutual support (peer) setting. Group members help themselves, help others and receive help. Self-help groups provide a non-judgemental atmosphere of trust and acceptance, role models for effective coping strategies and encourage a strong self-image and the determination to deal with the common problems of the group. Most importantly, members know that they are not alone in dealing with their problem. Self-help groups are usually autonomous and vary in structure and goals.
>
> ADVOCACY is defined as the act or process of leading the cause of another or of many. The transition from support to advocacy (while maintaining the support component) has occurred for many parent groups who focus on children with various handicapping conditions. These self-help groups have acted as the enabling catalyst that empowered parents to become effective advocates for their children as well as heighten societal awareness of the problems and needs of their children. Many of the parent groups have also developed powerful partnerships with professionals working together to affect changes related to treatment issues, services, policies and systems.

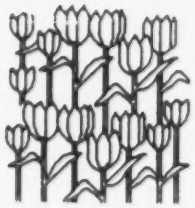
Developing a self-help/advocacy group for parents can be a long and frustrating task to undertake but a very gratifying and worthwhile endeavor not only for the parents and professionals but, in the long run, for the children.

After completing the workbook, you will:

- Have a beginning plan for the development of parent self-help/advocacy groups;
- Have some concrete plans for accessing parents of children with emotional problems;
- Have some options to deal with some of the barriers you will face in the development of these parent groups;
- Know who the agencies and professionals are in your community that serve children with emotional problems and their level of commitment to parents;
- Have an agenda for the first parent meeting;
- Have some ideas of the group's direction after the first several meetings;
- Have an idea of what the group will do together.

There are a number of appendices at the end of the workbook offered as examples to assist you. They are by no means exhaustive nor should they be used as anything but guides.

This workbook is intended as a guide and a catalyst. Be flexible to the needs of parents in your community and develop the parent groups to meet those special needs and qualities that make your community unique.



SOME BACKGROUND

During the past 15 years, self-help groups related to a variety of needs and concerns have proliferated. Consumers and persons with similar experiences have found a special kind of help from others that cannot be found anywhere else. In the mental health field alone there are groups for every kind of special need that you can think of. Two of the strongest groups of this kind are the Alliance for the Mentally Ill and Families for Mental Health. Started by family members of the adult mentally ill, they have mushroomed into national forces that have provided support and advocacy for the adult chronically mentally ill population and their families. However, there has not been an affinity between the parents of adults who are mentally ill and the parents of children and adolescents because the issues, problems, concerns, and treatment are so different.

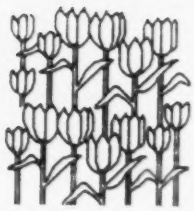
Another critical development in the past 15 years was the passage in 1974 of Public Law 94-142, the Education for All Handicapped Children Act. Parent training and involvement in decisions about the education of their children with special needs was established as a right under the legislation. The passage of this law came about through the efforts of parents of children with special needs banding together and advocating for their rights.

Why then haven't the parents of children with serious emotional problems been a part of these movements? There is no simple answer to this complex question. In listening to parents, however, it is quite clear that many have remained silent and isolated because of stigma, blame by professional helpers, feelings of hopelessness and helplessness, guilt, and the daily demands of living with a child who has emotional problems. Many parents have felt professionals, agencies and society blame them for their child's problems. Parents have talked about being apprehensive about confiding in their families, friends and neighbors as they, too, may blame them. Parents who have reached out for support and help often have found little help and even less support. We have heard over and over again that involved parents are viewed as intrusive; on the other hand, parents who do not seem to be involved are considered uncaring. They are damned if they do and damned if they don't.

Parents of children with emotional problems are often not invited to participate in already established self-help groups because their children are "different". Their children are included in Public Law 94-192 as children with special needs, but the support and training offered by existing parent groups is often geared only toward the child with a physical handicap or mental retardation.

Is it any wonder then that these special parents have not come forward nor been included in the already existing network of self-advocacy/support groups?

These attitudes and the isolation of many parents will present special problems for those trying to organize a parent group. The following sections will suggest ways to try to overcome some of these special problems. If you as the organizer have no personal experience with children who have serious emotional problems, the authors suggest you talk with parents who can share with you what it has been like for them. The authors further suggest if you are a parent organizing a group, you talk to professionals who can share with you what it has been like for them in their capacity as a professional.



WHY THE NEED FOR SELF-HELP/ADVOCACY GROUPS?

There are many reasons for self-help/advocacy groups for parents. Some of these are as follows:

FOR PARENTS:

- To help themselves, help others and receive help;
- To share experiences in a non-judgemental atmosphere of trust and acceptance;
- To provide role models for effective coping strategies;
- To encourage a strong self-image and the determination to deal with the common problems of the group;
- To become effective advocates for their children;
- To develop a collaborative relationship with professionals in the community;
- To educate the public on the needs and problems of children with emotional problems;
- To work together as allies with professionals to effect changes related to treatment issues, services, policies and systems.

FOR THE PROFESSIONALS:

- To be available as a valuable resource for parents;
- To develop a collaborative relationship with parents in the community;
- To obtain feedback regarding the services provided;
- To work together as allies with parents to effect changes related to treatment issues, services, policies, and systems;
- To have an opportunity to learn from parents what they want and feel they need;
- To relieve them from the pressure of believing that they have to have all the answers.

WHO ARE THE PARENTS OF EMOTIONALLY TROUBLED CHILDREN ?

The first step in developing parent groups is to define who the children are. In the State of Kansas we utilized the following definition:

A severely emotionally disturbed child or adolescent is one who:

A. Is under the age of 18, or is under the age of 21 and has been receiving services prior to the age of 18 that must be continued for maximum therapeutic benefits;

B. Exhibits severe behavioral, emotional, or social disabilities that consequently disrupt the child's or adolescent's academic and developmental progress, family and/or interpersonal relationships, often to the point that the child or adolescent is at risk for out-of-home placement or is placed out-of-home;

C. Has disabilities that have continued for an extended period of time or on the basis of specific diagnosis by a qualified professional are judged likely to continue for an extended period of time;

D. Has disabilities that cannot be attributed solely to intellectual, physical, or sensory deficits;

E. Frequently requires treatment delivered by an interdisciplinary team involving the family, courts, education, mental health and other family service agencies.

While this definition gives the broad parameters of the characteristics of the children with serious emotional problems, you must find out in your state what the current definition of this population is. You must be cautioned that focusing the groups on this specific definition may narrow the group of parents you reach. You must decide what makes the most sense for your community.

For many parents the language and labels attached to them and their child will hinder their willingness to participate in a self-help/advocacy group. One must consider carefully the choice of words utilized in establishing a group. One option is to leave the severity of the emotional problems out of the definition. Another option is to use words like "emotionally troubled", "behavior disordered" or "emotionally challenged". The use of words like "mentally ill" probably will scare people away because of the intense stigma that still exists in our society. To address the issue, one need only ask a group of parents what they think and what words will be least difficult for other parents.

Parents of children with emotional problems come from all walks of life and from all cultural backgrounds. They are both single and married and are of all racial groups. They are housewives, teachers, brick-layers, bankers, and doctors. These parents are rich and poor, formally educated and educated by experience. They are your neighbors and friends and maybe even your brother or sister. The one thing they share in common is that they have children who are experiencing emotional problems and they care very much about what happens to them.

Based on the authors' experience with families, many parents of children with emotional problems share feelings of frustration and guilt and many of them do not feel very good about themselves. Some have bought into the notion that somehow their parenting has caused their child's difficulties. Beside these feelings, some do not usually feel empowered to do anything about their situation. They have not been told that they are good parents nor that they have strengths and talents. They have not been treated with respect. They have not been given viable options or ways to cope effectively with the stress of living with a child with emotional problems. Many times they have had to relinquish the legal responsibility for their children to states in order to obtain mental health services. They have been faced with years of frustration trying to get the help they think their children need only to find that their choices are limited to one hour a week of outpatient treatment or placing their child in an institution. They have often felt like they could not handle one more day. They have felt alone in their situation and many times been afraid to ask for help. They do not know what their future holds in relation to their child and feelings of helplessness overwhelm them. They do not think anyone can or will understand their situation or offer any support in their efforts to deal with it.

All of these issues are extremely important if you are interested in developing parent groups. The issues listed are by no means exhaustive. Understanding of the issues and communicating this effectively will be the criteria by which other parents will evaluate your sincerity to assist them. Most parents will not readily become involved in a group unless they feel that the people starting the group empathize fully with their experience. If you are a parent of a child with emotional problems, none of this is new to you. If you are not, we strongly suggest that you connect with a parent who is interested in establishing a parent group. A partnership with a parent will move the process of development along much faster and be more credible for other parents of children with emotional problems.

With all of this in mind, you must know where to start in developing parent self-help/advocacy groups. You are again reminded that the following sections are only meant to be a guide and that the most effective plan will be the one that best fits you and your community. Use your creativity and be flexible. Remember if something isn't working try another approach!

GETTING STARTED

Develop your plan for starting the parent groups as you go through the rest of this workbook. You can utilize the planning sheet on page 22 as a guide to help you cover all the important steps.

STEPS FOR GETTING STARTED

- Creating a forum for self-help/advocacy group development
- Getting a meeting site
- Accessing parents
- Getting the word out
- Contacting parents

Each of the steps will be discussed in relation to the tasks that must be completed and the issues to be decided. Depending on your circumstances you can start the development of the group by contacting people at either the state level, the local level, or just with other parents. Some of the tasks are optional if they do not fit with your community. Remember, this is only a guide and you must decide what makes the best sense and what will work best for your situation. If you find the tasks outlined are unrealistic in terms of your time, other options will be discussed.

Creating A Forum For Family Empowerment

The fact that you are using this workbook probably means that you or someone in your state or local community recognizes the need to organize self-help/advocacy groups for parents of children with serious emotional problems. If this is not the case, you may want to first establish a forum for the groups to develop. One way to do this is to get the state level or community level service providers to recognize that they need the input of consumers of their services. The parents of these children are knowledgeable and know their children best. They, therefore, can provide these decision makers with the input they need to provide the best services for this difficult and underserved population.

A book that was published in 1982 by the Children's Defense Fund entitled Unclaimed Children, by Jane Knitzer, is still the most valuable resource on the issue of mental health services for children and adolescents. Another helpful article is in Children Today magazine, Vol. 15, Number 3, May-June 1986 issue, entitled "Parents and Mental Health Program Leaders: Working Together in

Kansas" by Richard Donner and John VanDenBerg. (See Appendix C to order these resources.) These both will give you some background ammunition to convince the program leaders in your state and/or local community of the importance of self-help/advocacy groups and parental input.

Once you have readied yourself with information there are many ways to get started, one approach to starting is to make contact with one or more of the following persons:

State Contact List

The state Child and Adolescent Service System Program (CASSP) administrator in the State Department of Mental Health (24 states now have these state level administrators);

The State Mental Health Representative for Children and Youth (SMHRCY) also in the State Department of Mental Health;

The state level Director of Special Education, in the State Department of Education;

The executive director of the State Mental Health Association;

The key leaders in your state for the mental health needs of children, whoever they are.

Another approach might be to identify the key mental health leaders in your community to access. It is sometimes helpful if you can take both of these approaches since local leaders are critical once the process is underway.

If you begin in this manner, once you have identified these key people, make an appointment to meet with them and gain their support in utilizing the expertise of parents to identify the strengths and problems with the service system for their children. These contacts should be of an informal nature where you have the opportunity to hear what your state or community is doing to meet the service needs of children with emotional problems. Use the time to get to know the administrator and share your interest in trying to improve the mental health services for youth. Share information about the needs of emotionally disturbed children. Explain how developing parent groups can be helpful to them in advocating for programs for this underserved population. If the state administrator has a definition of the population that he or she is focusing on, get a copy so you can use it to access other parents. Get the administrator to write an introductory letter to the mental health leaders in your community emphasizing the importance of self-help/advocacy groups and parental input and supporting the efforts to do so.

By the end of this step you should have:

- Become familiar with the issues and arguments regarding the importance of parent input to state and local mental health leaders;
- Identified the key mental health leaders for children's services in your state and/ or community;
- Set up meetings with the program leaders;
- Obtained their support and desire to have the input of parents, and
- Obtained necessary letters of introduction to the local community agencies.

If you find these tasks unrealistic in terms of your available time, the authors suggest you contact established parent groups in your community. Ask them how they started and brainstorm with them as to how you might best access the parents. If there are no established groups in your community see Appendix C for national resources which will be glad to help you.

Getting a Meeting Site

This second step is fairly straight forward and will not take a long time. Before you get ready to access other parents you should identify a place where you can have a meeting for the parent group and a tentative date for the first meeting.

You may have an idea in mind of an appropriate meeting site after talking to some of the key program leaders in your community. They may have offered to have the meeting at their agency or made suggestions of places that have appropriate rooms. It is important to select a site that is "neutral" to the parents. By neutral we mean that the site is not service connected.

There are many places that are more than willing to let a group use a room for a couple of hours. Check with people you know or groups that meet regularly to find out where they meet. Some possibilities include, but are not limited to:

- Churches
- Community centers
- Red Cross offices
- Banks
- Community colleges or universities or other places that are available at no charge to community groups.

Make the necessary contacts with the person who arranges for the use of the room giving him or her information about the purpose of the meeting. Ask for a written confirmation and a contact person for any problems that might arise. You will have to tell them a date and time for this first meeting and possible alternative dates so be sure to set dates far enough in advance so that you have plenty of time to accomplish the next three steps. Be sure to recontact the person after the final meeting date has been identified.

By the end of this step you should have:

- Obtained the names of places that have rooms available for community meetings;
- Identified a meeting site;
- Set a tentative date and time for the first meeting.

Accessing Parents

This third step is to get the names of other parents who might be interested in participating in a parent self-help/advocacy group. It is by far the most difficult and time consuming step in the process of developing parent groups. Because there is no centralized list of the parents, you will have to enlist the help of those persons who have contact with potential participants. Almost all of these parents come in contact with mental health centers, local child welfare agencies, schools, and private providers. One of your first tasks in this step will be to compile a list of all of the people and agencies that provide services to children with emotional problems and their families in your community. These will be both formal and informal service providers.

Use the following worksheet to begin to establish a working list of the service providers in your community. The worksheet is divided into six sections so that you can be sure to list the providers in each of the major systems that are involved with prospective participants. Use the telephone book or a community resource manual (available at most libraries) to get the necessary information. As you start contacting the people on the list add to it by asking the provider for other persons or agencies they know of that have contact with parents of children with emotional problems.

Community Resource Worksheet

1. SOCIAL SERVICE
   (Local child welfare agency. Specifically the staff in foster care, protective services and family support. Any state hospital for children or state juvenile facility).

TYPE OF PROVIDER	NAME AND TITLE OF CONTACT PERSON	ADDRESS/PHONE

2. EDUCATION
   (Local special education administrator, principals of primary and secondary schools that have special education classrooms, special education teachers, school nurse, school guidance counselor, parent teacher organizations in the schools, educational advocates, headstart programs, day care centers.)

TYPE OF PROVIDER	NAME AND TITLE OF CONTACT PERSON	ADDRESS/PHONE

3. MENTAL HEALTH

(Community mental health center, private mental health practitioners, child psychiatrists, child psychologists, and social workers, Mental Health Association, Alliance for the Mentally Ill, Families for Mental Health groups, Parents Anonymous groups and parent stress hotline)

TYPE OF PROVIDER	NAME AND TITLE OF CONTACT PERSON	ADDRESS/PHONE

4. HEALTH

(Public health department, pediatricians, family practitioners)

TYPE OF PROVIDER	NAME AND TITLE OF CONTACT PERSON	ADDRESS/PHONE

5. LEGAL

(Juvenile court judges, district and county attorneys, court service officers, police and sheriffs offices)

TYPE OF PROVIDER	NAME AND TITLE OF CONTACT PERSON	ADDRESS/PHONE

6. OTHER POSSIBLE PROVIDERS

(Clergy; foster parents; child advocate organizations; group and residential treatment centers, both public and private; private child placing agencies; community centers; others)

TYPE OF PROVIDER	NAME AND TITLE OF CONTACT PERSON	ADDRESS/PHONE

Fill out the list as comprehensively as you feel is necessary to get the names of the key providers of service for children with emotional problems in your community. You do not have to contact all of the people listed, but it will become clear as you make your initial contacts who the key persons are. This list can also be helpful to parents to know who to access for resources once the group gets formed.

The next set of tasks to complete are:

- Get letters of introduction from the state administrator to the key agencies on your list;
- Write up an explanation of why you want to locate parents of children with emotional problems that will be given to the providers;
- Write a letter or brochure inviting parents to attend the first meeting;
- Write a confidentiality form for the provider to use to get permission from the parents for you to contact them, or ask provider to make contact with families and distribute information.

The important thing to remember in the writing of these explanations is to give people all the necessary information they need: Purpose, date, time, meeting place, how to contact you, etc. Be careful to describe the population in ways that do not deter parents from participating.

The next task is to get ready to meet with the providers. Make contact with the directors of the programs and ask for a few minutes of their time to discuss your need for their assistance. If they have received a letter of introduction from a state level administrator, this entry will be fairly smooth.

These meetings with the providers are your key to accessing a large number of parents. A good strategy to gain their cooperation is to educate the providers on the potential benefits to them and to the families who will participate. The authors suggest that you emphasize that support groups do not provide treatment but rather an ongoing support network. Some of the providers will have biases against such groups and you may have to allay their fears and concerns. Sometimes these biases will be insurmountable and you will have to come up with strategies to address them.

Take time now to prepare yourself for some of the issues, barriers, and resistances that you may encounter in meetings with providers. Think of ways to handle them ahead of time so you do not get caught off guard or miss subtle communication. Use the following worksheet to help you begin to identify some of these potential issues and come up with strategies that are comfortable for you in handling them. You may even want to role play a meeting with a friend or colleague to practice various responses. The following is a list of potential issues you may confront. Come up with other issues that you might face and decide on ways to respond to them.

WORKSHEET TO OVERCOME ROADBLOCKS TO ACCESSING PARENTS

	BARRIERS	STRATEGY
1.	These parents don't need self help groups,they need treatment.	
2.	We can't give you the names, that is confidential.	
3.	Some of these parents have emotional problems themselves.	
4.	What will happen to our working relationship with these parents?	
5.	How will this help us?	
6.	We can't give out these brochures; our staff doesn't have time.	
7.	These parents are the cause of their child's problems.	
8.	Do you even want parents who have been in the state hospital?	
9.	What about parents who have adopted the child with emotional problems?	
10.	Some of these parents are more dysfunctional than the children.	
11.	How will this help the children?	
12.	These parents don't want to discuss their problems with other parents.	
13.	Other	

The important thing to remember when dealing with providers is to appeal to their desire to help others and be responsive to the people they serve. Emphasize how important they are in helping with this effort. Sometimes the providers will not raise the issues and seem to be supportive. If they don't bring up some of the important issues, take the initiative to raise them yourself.

Make an outline of the points you want to be sure to cover in the meetings with providers. Use the following checklist in making your outline.

CHEKLIST OF POINTS TO COVER WITH PROVIDERS

___ • Discuss how the information will be used and what will happen in the meetings.

___ • Discuss the reasons for self-help/advocacy groups and talk about support and advocacy.

___ • Emphasize letting the parents decide if they want to participate.

___ • Emphasize that support groups are not for treatment.

___ • Acknowledge that you know this will take some of their own time as well as their staff's time.

___ • Emphasize the benefits the group will provide for them.

___ • Give them plenty of time to get the information out to the parents.

___ • Offer to meet with the staff at their next staff meeting to discuss any issues that the staff raise.

___ • Tell them how to reach you for any questions and when you will be back in touch with the person they designate to get the names of interested parents.

When the meeting is ready to end be sure that you have left with the provider copies of the following:

Material for Providers

- Information sheet for professionals
- Definition of the population
- Confidentiality form
- Brochure/flyer sheet for parents

If you have the money, give the provider the brochure or flyer sheet for parents in postage paid envelopes to send out to the parents with another prepaid envelope for the parents to send you their name. This also saves them from having to get the confidentiality form filled out.

If your community is in a rural area or you are trying to organize a group with an ethnic population, you must be sensitive to some special issues. In rural communities be sure to allow for more time for the providers to contact the parents. These families have less contact with providers and services are less accessible. Remember that parents in rural areas do not have easy access to baby-sitting and may have to travel further to a meeting. There are many different cultural norms in the rural communities. Understanding the values and norms in your area will help you to effectively access parents who might be interested in participating in a parent group. Once you have made contact with parents you may have to do more networking with them by phone and with letters, rather then trying to get them to come to a meeting. Be flexible in the plan for your design for the special needs of your area.

To effectively organize a parent group in culturally diverse communities, it is best to utilize the resources in the ethnic community. If you are not of the same ethnic extraction, try to find someone in the community who is and is willing to facilitate the development of the group. You can be a resource to them. Locate the leaders in the community who are involved in ethnic organizations. Again, you have to be sensitive to the different norms and values of the group and have them set up the meetings. Many times churches or community centers in these areas can be very helpful in facilitating the development of the group. Holding the first meeting right after an already planned ethnic event will enhance the chances of your making contact with a number of parents.

By the end of this step you will have:

- Completed a list of all of the formal and informal service providers in your community;
- Obtained letters of introduction sent from the state administrator;
- Written some information for providers;
- Written brochure or flyer for parents;
- Written a sample confidentiality form;
- Rehearsed ways to handle potential roadblocks in meetings with providers;
- Set up meetings with the key providers in your community;
- Made an outline of the important points to cover in the meetings;
- Made alterations in your plan to meet the special needs of your area or community.

Getting the Word Out

This step is to decide the ways you want to publicize the information regarding the formation of a parent self-help/advocacy group. This step can be done simultaneously with the previous step or, in some instances, it may replace the previous step. The following are some suggested strategies for "getting the word out."

Possible Ways to Publicize The Meeting

- Place notices in the family section of the newspaper;
- Get an article about the formation of the group in the newspaper;
- Get the meeting announced on TV and community service radio spots;
- Place notices in church bulletins;
- Hand out notices at a Parent Teacher Association meeting;
- Send out notices to all parents whose children are in Special Education classrooms;

- Put up posters in launderettes, malls, supermarkets, service organizations, etc.;
- Leave brochures at all the formal and informal service providers, utilizing the list you compiled in the previous section;
- Set up booths at health fairs, in malls, or supermarkets;
- Visit waiting rooms of children's psychiatric hospitals to meet parents;

(For sample announcements see Appendices A and B)

A NOTICE SHOULD ALWAYS INCLUDE

- Purpose of the group
- Date of the meeting
- Time of the meeting
- Place of the meeting
- Your phone number for questions

By the end of this step you should have:

- Decided on the ways you will get the word out to parents.
- Designed the necessary information to be shared.

Contacting the Parents

The final step in getting started is to contact the other parents who have expressed an interest in being a part of the group. Your communication with them will pay off if you remember some of the issues discussed earlier. Direct contact with the parents yourself is best. If you are a professional, arrange for this contact to be by another parent. Parents will more readily respond to a parent who has similar experiences and can share their desire to be involved in a parent group.

The call should be made on weekends or evenings when the chances are greater that parents will be home. Make a list of the things you want to be sure to cover in the phone call. Use the following checklist as a guide for your list.

PARENT CONTACT CHECKLIST

___ • Confirm the parents' willingness to participate in the first meeting.

___ • Discuss the need for a self-help/advocacy group (including the difference between self-help and advocacy) and why belonging to a group would be so beneficial.

___ • Remind them of the time and place of the meeting.

___ • Be sure they have directions to the meeting and the room number in which it will be held.

___ • Check to see if they need help with transportation or baby sitting. (ONLY IF YOU ARE ABLE TO ASSIST IF THERE IS A PROBLEM.)

___ • Ask them if they know of other parents who might be interested in attending that you could contact or that they might invite.

___ • Thank them for their interest and let them know you are looking forward to meeting them.

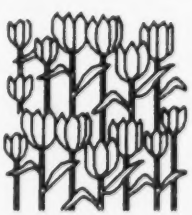
Be willing to talk to them as long as needed since they may have a lot to share and may not have had the opportunity to do so before.

By the end of this step you should have:

- A contact list of interested parents;
- An outline of things to cover when contacting the parents;
- A list of potential participants;

YOUR EFFORTS HAVE FINALLY BEEN REALIZED!

On the next page is a planning check sheet for the parent group.



Summary Planning Sheet for Beginning A Parent Self-Advocacy/Support Group

	Strategy	Who Will Do It?	By When?
Educate Yourself			
Identify Population			
Create a Forum State Level Local level Letters of Introduction			
Get a Meeting Site Obtain a meeting site Set a date for first meeting			

	Strategy	Who Will Do It?	By When?
Access Parents Develop local providers' list Prepare written information for providers Set meetings with providers Prepare outline for meetings with providers Rehearse ways to handle potential road blocks			
Get the Word Out Media Notices Posters/flyers Places to leave notices			
Contact Parents Develop contact list of parents Outline things to cover with parents			

THE FIRST MEETING

Now that you have completed the tasks outlined on the previous pages you should set up an agenda. You must also think about seating arrangements since this can exert a strong influence on group dynamics. A classroom arrangement with the organizer at the front and everyone facing him/her would be inappropriate. A circle arrangement is suggested in terms of each participant being able to make eye contact as well as putting all participants on an equal footing.

The meeting should begin with introductions. The organizer should explain that the purpose of the meeting is to give the parents the opportunity to form a self-help/advocacy group. Some time should be spent discussing self-help and advocacy and the difference between the two. Be sure to allow time for a question and answer period.

After the above discussion,a parent should be asked to share his/her experiences as a parent of a child or adolescent who has emotional problems. If the organizer is a parent it would be appropriate for him/her to do this. If the organizer is a professional, it would be helpful to have a parent prepared to take this lead. The first meeting should provide the opportunity for parents to share some of their experiences. This should be done on a voluntary basis. The organizer should facilitate this sharing time.

The following excerpt is from a speech made at a Kansas CASSP conference in October of 1985, by Cindy Boatman and captures what it was like for her.

> "I am the mother of a 16 year old mentally and emotionally disturbed child. We have spent many, many hours in counseling with him. After a long period of time and beating our heads against many brick walls, we came to the conclusion that there was no help for either him or for us as parents. We kind of fell through the cracks....
>
> Through a Family Input meeting we met some other parents of kids that were like ours, and to my amazement, I found out we weren't all by ourselves. There was somebody else out there saying, ' This is the pits. This is without a doubt the most horrible mess,' and not feel bad because I wasn't a bad mom or his dad wasn't a bad dad or that the other kids were crummy or that our family was a real screwed up mess. They understood how it felt and that there wasn't any place to go, that we as parents didn't even know who to call and ask. It was wonderful.

So we have maintained this little group of us that originally got together. We still haven't progressed a great deal but we are hoping we can progress to the point of having some sort of a group where we can hold ourselves together and still get some action. Some action for the parents and some action for the siblings within a family. We aren't bad parents. These things happen and it's an unfortunate thing, but we parents are tough and need to be included. We need to know what is happening. We need to feel like somebody cares, that we're not just out there to pay the bills or that we're going to go away. I don't know one of us who is just going to hide away or slip underneath the carpeting. We're going to be there and we care what happens. Until people in the community can accept this and realize that we are out there, the situation is not going to get any better for that child or that family or for us as parents or for anybody else."

As the meeting progresses, parents may share anecdotes about their child that are humorous to them and other parents. Parents will also share experiences that are frustrating and stressful. For many, this may be the first time they have had the opportunity to share in an accepting and non-judgemental atmosphere.

If the group has been organized by a professional or with the assistance of a professional, he/she must discuss what his/her role will be. Explain that the professional's role will change from organizer to resource person. Depending on the wishes of the group, he/she may continue to be involved with the group for the next several meetings. The role of the professional can be discussed at length at the next meeting.

By the end of the meeting parents hopefully will want to continue to meet. The organizer should be ready to suggest times and dates so this decision can be made before everyone leaves. This is also a good time to suggest exchanging telephone numbers.

Thank everyone for attending.

After the first meeting send out a note to all the parents to remind them of the next meeting. Also ask them if they know of other parents who might be interested in attending the next meeting. This is also a good time to send a thank-you note to all of the people who helped to access parents. Let them know that the meeting took place and you want their continued support.

CHECKLIST FOR THE FIRST MEETING

___ • Seating arrangements.

___ • Open with introductions.

___ • Describe purpose of the meeting. (Question and answer period.)

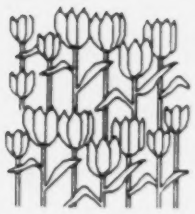
___ • Sharing of experiences.

___ • Discuss the role of the professional (leave time for further discussion at the second meeting).

___ • Set a second meeting date and time.

___ • Begin establishing a network with name and telephone exchange.

___ • Thank everyone for attending.



AFTER THE GROUP IS FORMED

If the group decides in the first or subsequent meetings that they want to organize into a self-help/advocacy group, there are a number of resources available to help them do this. A couple of good resources have been developed by the Pacer Center in Minnesota and the Coordinating Council for Handicapped Children in Chicago. (See Appendix C.) You can find resources in your community also by contacting existing self-help groups or the sponsoring groups that were listed in the previous section to assist you. Remember that all the participants together have a wealth of hidden talents and competencies and will probably have all the necessary resources and ideas about how they want to organize.

Don't be concerned if the group doesn't decide what they want to do right away. Goals can wait -- groups are not built overnight. Use the initial meetings to get to know one another and build an atmosphere of trust.

After the first several meetings the group should begin to discuss leadership issues. They may decide to elect a chairperson, rotating leadership or shared leadership. They may also decide that the organizer (if a professional) remain involved with the group until this issue is resolved. Be patient and make sure the group feels comfortable with their decision in terms of leadership. The organizer might point out during this discussion that shared responsibility is the key to shared leadership. The more people that share in the work, the more people will feel a sense of participation and ownership!

A concern that might come up at this time is attendance. Do not judge the success of the group by the attendance. Some members may have a lot of responsibilities and may not be able to or want to be active participants--they must want to be part of the network. Find ways to touch base with them even if just a telephone call. Some parents may attend meetings when they are in crisis and never show up again. They may still want to be considered part of the network. Other parents may attend one or two meetings and decide that the group is not for them.

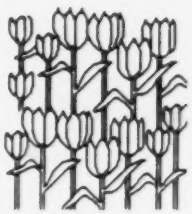
After several meetings the group should establish some ground rules around the following issues:

- How discussions are held;
- What to do when some members talk too much;
- Allowing outside people to observe the group;
- Discussing members not present at the meeting;
- Starting and ending on time;

- Refreshments;
- Smoking vs. non-smoking.

The ground rules will vary from group to group.

The authors assume the group (after several meetings) will still be focusing on support, getting to know one another and slowly building trust. Again, we urge you not to rush the members to make decisions on goals and objectives. This will come with time!



WHAT THE GROUP WILL DO TOGETHER

After the group is formed and somewhat secure,the group will decide what it is they want to do (goals) and how they will do it.

The goals of one group may be to focus on support only. Another group may have a goal of working in partnership with professionals in their community to improve services for children. Another group may set a goal to become effective advocates for their children and other children (case advocacy). Goal setting is an involved process and will not happen overnight.

The group may decide to publish a newsletter. This would expand the group's network, provide information, recruit new members and serve as a forum for readers' opinions.

The group could decide to develop a speakers bureau of parents who would be willing to make presentations at schools, workshops, etc..

Some groups may want to establish a HOTLINE for parents in their community.

Some groups may become action groups. They will demonstrate, organize town meetings, hold press conferences and plan events to enlighten the public on the plight of children and adolescents with severe emotional problems.

Most groups will decide to develop a lecture series covering such topics as:

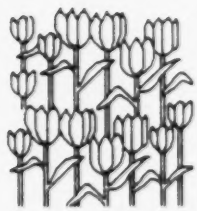
- Understanding the Individual Education Plan (IEP)and how to be an educational advocate for your child;
- Identifying available resources in the community and how to access them;
- Learning how to negotiate the multiple systems in your community;
- Developing respite care;
- Obtaining information on medication and diagnoses.

Topics and speakers should be a group decision.

Some groups may decide to develop an advocacy training program. They can utilize their own expertise and also bring trainers in from the outside.

Each group will be unique and will find its own role whether it be support and/or advocacy, a vocal voice in the community and the state, a visible group demonstrating every other week or a small group of people meeting once a month over tea in a diner for sharing and for helping.

Developing parent self-help/advocacy groups with parents of children with emotional problems can be done. A key to the successful development is to educate yourself and learn from each other. If you are a professional, work in a partnership with a parent to start the group. Learn from the experience of parents of children with emotional problems. If you are a parent, utilize your expertise and understanding of the issues to access other parents to be a part of the group. Effective development of the group will depend on your ability to be flexible and creative. Be responsive to the unique needs of your community. Be patient and understanding. Be hopeful and optimistic. Remember to hang in there and you will get results.



APPENDIX A
EXAMPLES OF POSTERS OR FLYERS

PIN

PARENTS INVOLVED NETWORK

A self-help/advocacy group for parents of children and adolescents with emotional problems

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WHAT IS PARENTS INVOLVED NETWORK (PIN PROJECT)?

Self-help/advocacy groups for parents of emotionally disturbed children and adolescents.

WHAT DOES PARENTS INVOLVED NETWORK DO?

PIN provides parents an opportunity to come together to share common concerns and experiences, exchange information, identify resources and learn how to advocate effectively for their children.

WHEN?

First and third Thursday of every month

WHERE?

Room 1007, 311 South Juniper Street,
Philadelphia, PA

TIME?

7:00 p.m.

FOR FURTHER INFORMATION CALL:

Glenda Fine, 215-735-2465

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PLEASE POST

PIN

PARENTS INVOLVED NETWORK

A self-help/advocacy group for parents of children and adolescents with emotional problems

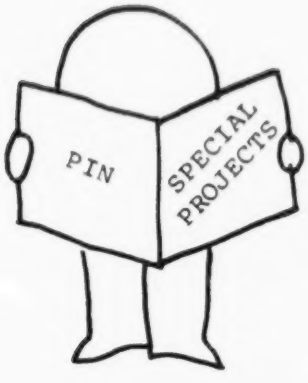
---

WHO: SALLY TOWNE - PROJECT ACCESS
MENTAL HEALTH ASSOCIATION OF
SOUTHEASTERN PENNSYLVANIA

WHAT: "HOW CAN I FIND TIME FOR MYSELF"

WHEN: THURSDAY, DECEMBER 4, 1986
7:00 PM

WHERE: 311 South Juniper Street
Philadelphia, PA
Room 1007



For more information contact:
Glenda Fine, Mental Health Association
of Southeastern Pennsylvania
735-2465

PLEASE POST

PARENT SUPPORT GROUP

DATE: Thursday,
November 13, 1986

TIME: 7:00 P.M.

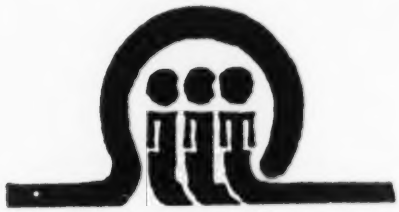
PLACE: Parent Center
1621 SW 32nd Street
Topeka, Kansas
(Green House behind Countryside Church)

WHO: Parents of Children and Adolescents with Emotional Problems

WHY: Informal meeting for parents to organize a Parent-to-Parent network to share common concerns and experiences and exchange information.

FOR FURTHER INFORMATION:

Call Barbara Huff
267-4270



APPENDIX B
EXAMPLES OF NEWSPAPER NOTICES

WANTED

PARENTS TO SHARE THE FRUSTRATIONS OF PARENTING AN EMOTIONALLY TROUBLED KID. TALKING WITH OTHERS CAN MAKE A DIFFERENCE!

JOIN OUR SELF-HELP GROUP FOR SUPPORT, AND INFORMATION ABOUT AVAILABLE RESOURCES; OR CALL IF YOU JUST NEED TO TALK . . .

PARENTS ENCOURAGED NETWORK—215-735-2465

Parents Involved Networks: Dr. William Hetznecker, child psychiatrist, discusses who is the emotionally disturbed child/adolescent, Aug. 8, 7 p.m., Mental Health Association, 311 S. Juniper St. (735-2465) Free.

Self-Help

Self-Help/Advocacy group for parents of children and adolescents with emotional problems will meet tomorrow at 7 p.m. at the Mental Health Association, 311 S. Juniper St., Philadelphia. For information, call 735-2465. Admission is free.

The Developmental Disabilities Planner

PARENTS OF CHILDREN WITH EMOTIONAL DISORDERS JOIN FORCES

A self-help and advocacy group for parents of children and adolescents with emotional disorders has been formed in the Philadelphia area. Called Parents Involved Network (PIN), it provides these parents with an opportunity to share common concerns, provide mutual support, and help each other in dealing with the mental health and education systems.

PIN is a project of the Mental Health Association of Southeastern Pennsylvania, and is supported by a grant from the Pew Memorial Trust.

For more information about Parents Involved Network or about starting a similar group in your area, contact Glenda Fine, Mental Health Association of Southeastern PA, 311 South Juniper St., Philadelphia, PA 19107, (215) 735-2465.

Mary Anne Delaney, Child Psychiatrist, will discuss Psychiatric Hospitalization for Children/Adolescents tomorrow at 7 p.m., at the Mental Health Association, 311 S. Juniper St., Philadelphia, room 1007. The meeting is sponsored by Parents Involved Network. For information, call 735-2465.

Involved Parents: A self-helpgroup for parents of children and adolescents with emotional problems, Parents Involved Network, will meet March 20, 7 p.m., at the Mental Health Association, 311 S. Juniper St., Philadelphia. Free.
Information: 735-2465.

BEST COPY AVAILABLE

APPENDIX C

References and National Resources

Children Today, May-June, 1986, Volume 15, Number 3, " Parents and Mental Health Program Leaders: Working Together in Kansas." Department of Health and Human Services. Editor. Room 356-G, 200 Independence Ave., SW Washington,D. C. 20201

Unclaimed Children, Jane Knitzer, 1982.
Children's Defense Fund
122 C Street NW
4th Floor
Washington, D. C. 20001
202- 628-8787

National Mental Health Association
1021 Prince Street
Arlington, VA 22314
703-684-7722

Laurie Flynn, Executive Director
National Alliance for the Mentally Ill
1901 North Fort Myer Drive
Suite 500
Arlington, VA 22209
703-524-7600

PACER Center Inc.
4826 Chicago Ave. South
Minneapolis, MN 55417
612-827-2966
(for "A Guidebook for Parents of Children With Emotional Disorders")

Coordinating Council for Handicapped Children
220 S State Street, Room 412
Chicago, IL 60604
312-939-3513
(for "How to Organize an Effective Parent/ Advocacy Group and Move Bureaucracies"

Phyllis Magrab, Director
CASSP Technical Assistance Center
Georgetown University Child Development Center
3800 Reservoir Road, NW
Washington, D.C. 20007
202-625-7675
(for this workbook and numerous other related materials)

Barbara Friesen, Director
Families as Allies Project
Research and Training Center
Portland State University
P.O. Box 751
Portland, Oregon 97207
503-229-4040
(for a National Directory of Parent Organizations
and an Annotated Bibliography of Parent Professional
Collaboration and Self-Help Groups)